

February 6, 2020

Dr. Joshua Gordon, M.D., Ph.D.
Director, National Institute of Mental Health and
Chair, Interagency Autism Coordinating Committee

Dr. Susan Daniels, Ph.D.
Director, Office of Autism Research Coordination

Greetings Dr. Gordon and Dr. Daniels,

We celebrated the passage of the Autism CARES Act and your leadership of the Interagency Autism Coordinating Committee (IACC) ensuring the advancement of critically important research that impacts individuals of all ages on the autism spectrum and their families. Thank you for your passionate, steady and tireless pursuits.

In October 2019, the Autism Housing Network and The Daniel Jordan Fiddle Foundation Center for Public Policy at the First Place Global Leadership Institute gathered experts from across the country for a Neuro-Inclusive Real Estate Think Tank facilitated by the Arizona State University Morrison Institute on Public Policy. These representatives from the public, private, not-for-profit and philanthropic sectors recognize the residential crisis stems from 1 in every 59 children are on the autism spectrum, yet residential support is currently available to only 1 in 498 of the population.¹ We gathered to identify barriers and discuss opportunities for major expansion of a supportive housing marketplace that is needed to meet the ever-increasing and broad demand for more options.

This second jointly sponsored Think Tank identified key areas where research is needed to address several pressing concerns:

- 1) Creation of a universal nomenclature of supportive housing models and segmentation of the population needing long-term supports and services based on need and not simply diagnosis

¹ pg 21, *State of the States in I/DD, Tenth Edition 2015*, University of Colorado

- 2) Well-trained direct support providers with a respected career path as to not lose, but gain, quality professionals to the field including value-based versus commodity-based compensation where outcomes, not hours, are the focus
- 3) Data on and drivers of outcomes, ensuring we move the needle on quality of life, impacted by more than the physical home setting
- 4) Marketplace reports identifying demand, economic and societal impact
- 5) Use of existing, data-driven systems demonstrating success, developed in the private and not-for-profit sectors, which could significantly impact the field of housing development and service provisions currently bound by HUD and Medicaid funding streams and regulations

The current demand for more diverse and enhanced housing choices is not unique to the autistic population. Housing has been underscored as a major Social Determinant of Health by the Center for Disease Control (CDC). The CDC launched a [Healthy People 2020](#) initiative, highlighting the importance of “creat[ing] social and physical environments that promote good health for all” as one of their four overarching goals for the decade. In AARP’s new report, [‘Making Room: Housing for a Changing America,’](#) they underscore a shift in America’s demographics and lifestyles that is not reflected in the current housing stock and highlights diverse emerging solutions from high-amenity housing for singles to flexible, intergenerational, single-family home properties. And through [Home Matters America](#), recognizes homes represent “safe, nurturing environment(s) with access to quality education, healthcare, public spaces and community services.”

We believe innovative housing models like the properties and their representatives who spoke at the last IACC Housing Work Group, “Addressing the Housing Needs of People on the Autism Spectrum” on July 23, 2019, must be studied as they provide evidence that the built environment combined with technology, individualized service delivery, and integration with the broader community, may deliver better outcomes for the broad neurodiverse population in a more cost effective manner.

Unfortunately, barriers to innovation exist. Due to lack of research, current policy and regulations regarding federal and state funding streams are based largely on ideology rather than evidence-based practice. We are joined by 85 organizations that have signed onto this letter to strongly encourage IACC to:

1. Substantially increase research dollars for Question 5 of the 2017 IACC Strategic Plan, “What Kinds of Services and Supports are Needed to Maximize

Quality of Life for People on the Autism Spectrum?” which received only 5% of research funding²

2. Substantially increase research dollars for Question 6 of the 2017 IACC Strategic Plan, “How Can We Meet the Needs of People with ASD as They Progress into and through Adulthood?,” which received only 2% of research funding³
3. Continue the IACC Housing Workgroup which last convened on July 23, 2019, “Addressing the Housing Needs of People on the Autism Spectrum”

As active participants in the development of a better future, we are investing considerable time and effort to collaborate with and engage industry leaders and those within and outside of the ‘autism’ community as we develop a path for a new wave of supportive housing opportunities.

Thank you again for your leadership! We look forward to more opportunities to collaborate on research into home, community, services and lifespan issues for autistic adults and others with intellectual/developmental disabilities.

Yours sincerely,

Desiree Kameka
Director & Project Leader
[Autism Housing Network](#)

Denise D. Resnik
Founder, President & CEO
[First Place AZ Global Leadership Institute](#)



85 Joint Letter Sign-on Organizations

A+ Autism Solutions
A New Leaf
A Place to Call Home
A Voice of Reason
ACCSES
Abundant Life Autism
Aidan’s House
Ascendigo Autism Services

² Pg 21, https://iacc.hhs.gov/publications/portfolio-analysis/2016/portfolio_analysis_2016.pdf

³ Pg 21, https://iacc.hhs.gov/publications/portfolio-analysis/2016/portfolio_analysis_2016.pdf

Autism Housing Development Corporation
Autism Housing Pathways
Autism Model School
Autism New Jersey
Autism Project of Palm Beach County
Autism Science Foundation
Autism Society San Francisco Bay Area
Autism Treatment Center
Avondale House
Bergen County's United Way
Bittersweet Farms
BrightStone, Inc.
CJM Wealth Management
Camp Krem
Camphill California
Camping Unlimited for the Developmentally Disabled
Cape Cod Village
Casa de Amma
Center for Autism and Related Disabilities (University of Miami)
Chapel Haven
Circle Square Foundation
Clearwater Ranch Community
Coastal Haven Families, LLC
Common Roots Farm
Connected Community of Wilmington
Creative Housing Solutions
Disability Opportunity Fund
Enabling Spaces
Endeavor 21+
Escher Fund for Autism
Faison Center
Farmsteads of New England
First Place AZ
Golden Heart Ranch
HOPE North Carolina, Inc.
Have a Heart, Inc.
Help Autism Center
Home of Our Own, Inc.
Home Together, Inc.
Homes for Life Foundation
Homes to Aspire
Independentworks
Integrated Living Opportunities
Ken Anderson Alliance
LOMAH

LTO Ventures
L'Arche Jacksonville
Life Services Alternatives
LittleStar
Living Unlimited
Madison House Autism Foundation
Mandy's Farm
Marbridge
Mustang Court Community
National Council on Severe Autism
New Danville
Next Step Strategies, Inc.
Noah Homes
OASIS tlc
PANDH (Parent Advocates of Neuro-Developmental Disability Housing)
Parents With A Plan
Partners4Housing
Prader-Willi California Foundation
Rusty's Morning Star Ranch
Rutgers Center for Adult Autism Services
SOS Health Care, Inc.
Southing Fields
Sunflower Hill
Tall Tales Ranch
Terebinth Group
The Arc of the Eastern Panhandle
The Baddour Center
The Kelsey
The Neighbor Bridge
United Way Bergen County
Urban Autism Solutions
Vanguard Landing